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## Stigma and stigma interventions related to leprosy and tuberculosis in Thailand

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2014

### **document version**

Publisher's PDF, also known as Version of record

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### **citation for published version (APA)**

Sermrittirong, S. (2014). *Stigma and stigma interventions related to leprosy and tuberculosis in Thailand*. [PhD-Thesis – Research external, graduation internal, Vrije Universiteit Amsterdam]. Ridderprint.

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## Summary

Stigma related to leprosy and tuberculosis may prevent those affected by these diseases to enjoy their rights to health, which includes timely and appropriate care. To interrupt the cycle of stigma, the main research question this thesis addresses is: *'How to reduce stigma related to leprosy and tuberculosis?'*

This research question is broken down into six sub-questions:

*What are the causes and determinants of stigma related to leprosy and tuberculosis?*

*What are the characteristics of stigmatising behaviours manifested towards people affected by leprosy and tuberculosis?*

*What is the impact of stigma on people affected by leprosy and tuberculosis?*

*What are community members' and health workers' perceptions regarding leprosy and tuberculosis stigmatisation?*

*What kinds of intervention could be launched to reduce stigma related to leprosy and tuberculosis?*

*What are the changes in the community and the affected persons brought about by the interventions?*

In order to answer these questions, the thesis employed both qualitative and quantitative approaches. A systematic literature review was conducted to investigate the causes, determinants, manifestations and impact of stigma. It also identified various de-stigmatising interventions. A pre-intervention survey investigated stigma in the study areas, namely four districts in the north-eastern region of Thailand. The de-stigmatising interventions were then developed and piloted by the three groups of local people and related organisations, including people affected by leprosy and tuberculosis: a formal health care group, a local volunteer group and a self-help group. Two monitoring and evaluation exercises were conducted between the interventions. The effectiveness of the interventions was determined by comparing leprosy-related stigma before and after them.

## Part 1: Theory

This part consists of Chapters 4–6.

### Chapter 4: Stigma in leprosy: concepts, causes and determinants

This chapter presents the results of the systematic review of the concepts, causes and determinants of stigma in leprosy. It suggests that the concept of stigma involves not only characteristics that are considered undesirable, but also the social context of the individual or group. The causes and determinants of stigma related to leprosy are the external

manifestations of the disease, cultural and religious beliefs, fear of transmission, association with people considered inferior and public health-related interventions. Stigma related to tuberculosis is mentioned in the discussion and concluding section.

#### **Chapter 5: Stigma in leprosy: manifestations, effects and dynamics**

This chapter presents the results of a systematic review of the manifestations, effects and dynamics of stigma in leprosy. It finds that the main manifestations of stigma are that people affected by leprosy tried to conceal their disease and practised self-isolation. Communities expressed their negative attitudes towards people affected by leprosy by avoiding them, forcing them to live in a leprosy colony, and refusing to share public transport with them. These manifestations have a negative physical, psychological and socio-economic impact on the people affected and also on their families. The manifestations of stigma and its effects may differ depending on a person's external appearance, status, gender and social distance from those who are stigmatising. Stigma related to tuberculosis is mentioned in the discussion and concluding sections.

#### **Chapter 6: How to reduce stigma in leprosy – a systematic literature review**

This chapter presents the results of another systematic review. It mentions that interventions with some evidence of effectiveness in terms of reducing stigma are the integration of leprosy programmes with general health care, Information Education and Communication (IEC) programmes, and socio-economic rehabilitation.

### **Part 2: The reality of stigma related to leprosy and tuberculosis in Thailand**

This part consists of chapters 7 and 8.

#### **Chapter 7: Comparing the perception of community members towards leprosy and tuberculosis stigmatisation**

This chapter presents the quantitative measurement of community members' perception of the stigmatisation of those affected by leprosy and tuberculosis. It was found that they perceived that the community had stigmatised people affected by leprosy and tuberculosis but that they were more aware of community stigma towards leprosy than towards tuberculosis, particularly in terms of shame, embarrassment, and problems in getting married.

#### **Chapter 8: Assessing the attitudes and perceptions of community members and health workers regarding the stigmatisation of leprosy.**

This chapter presents the qualitative and quantitative assessment of the attitudes and perceptions of community members and health workers regarding the stigmatisation of people affected by leprosy. It was found that both community members and health workers had negative attitudes towards leprosy and perceived that those affected by it were being stigmatised. Community members and health workers also perceived leprosy as a disease

that involves disability, is incurable and hereditary, and is associated with dirtiness and oozing, foul-smelling wounds.

### **Part 3: De-stigmatising interventions**

This part consists of chapters 9 and 10.

#### **Chapter 9: Addressing stigma related to leprosy**

This chapter presents the stigma interventions launched in three districts of Chaiyaphum province. It was found that the self-esteem and social participation of those involved in self-help groups were changed more than among members of the local volunteer group and that there was no change among members of the formal health care group.

#### **Chapter 10: The effectiveness of de-stigmatising interventions**

This chapter presents the quantitative measurement of de-stigmatising interventions. It was found that there was a significant reduction of perceived stigma among community members and health workers in the area where de-stigmatising interventions were launched by the local volunteer and self-help groups, but no reduction of perceived stigma among community members or health workers in the area where de-stigmatising interventions were launched by the formal health care group. In all areas there remained a high percentage of people manifesting stigmatising attitudes and perceptions.

### **General discussion**

**Chapter 11:** Each research sub-question is briefly answered with broader discussion. The validity of the findings, the recommendations for future de-stigmatising interventions and research, lessons learned, and the sustaining of the interventions then follow.